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Editor: Robert Levy

Contributors:

- Charles Nutt
- Nicole Patterson
- Rebecca Donabed
- Robert Balderama
- Wesley Witherspoon
- Lisa Cooley
- Paul Mansell
- Eric Aguilar
- Goldie House

Message from 2022-2024 SSAN Officers

By Charles Nutt, North State Regional SSAN Representative
Nicole Patterson, DDS SSAN Representative
Rebecca Donabed, Sequoia Regional SSAN Representative

Leadership is defined as “the act of leading a group of people or an organization.” However, a leader isn’t simply someone in a high-level position who tells others what to do – there’s much more to it than that. Leadership isn’t “one-size-fits-all,” because everyone has their own personality, perspective, and their own learning style. Understanding different leadership styles is a great way to paint an accurate picture of what leadership is. So here is a little bit about the 2022–2024 SSAN Officers.



My name is Charles Nutt and I am the 2022-2024 SSAN Chair and I wanted to take a moment to tell you about myself. I started his leadership journey in the Paradise Chapter of People First of California, where I eventually became Vice-President.

In college, I studied Business Computer Science and joined an Honor Society called Sigma Alpha Pi which is a credited honor society for leadership and success. Eventually I served as Information Technology Coordinator for Sigma Alpha Pi and joined the Associate Students at Butte College serving as Inter Club Council Director. After finishing college, I wanted to continue my leadership development and asked my service coordinator for ideas on how I could continue to serve and was told about the State Council on Developmental Disabilities and was encouraged to get connected with the local office. I advised the local office (then Area Board 2) and was encouraged to apply to be a Councilmember on the statewide SCDD board.

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VOICES of SSAN

March 2023

Volume 32

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Through my work with SCDD, I learned about SSAN and saw it as an opportunity to connect with other disability advocates and leaders from across the state. I served as Secretary on SSAN, but as the needs of the Council changed, I decided to step down from SSAN to give others a chance to lead and focus my energy on Council need. I eventually was elected to serve as Vice-Chair on the State Council on Developmental Disabilities. Currently, I serve as the Chair of the Far Northern Regional Center (FNRC) Self Determination Advisory Committee (SDAC) in an effort to increase the number of people enrolled in self-determination and am excited to be involved with SSAN. I hope that through his leadership, I am able to listen and learn from my fellow officers and collaborate to find solutions and build a strong ship to strengthen self-advocacy in California. I would like to strengthen the self-determination program, educate others about resources, bring motivational speakers to SSAN and focus on getting youth involved in advocacy.



My Name is Nicole Patterson. I am the new Statewide Self Advocacy Network (SSAN) Vice Chairperson. I have been involved with the SSAN since the beginning. My vision for the SSAN during this term is that we become even more of a driving force when it comes to people with disabilities gaining services and supports, youth engagement, employment, growing self-determination in the state of California, and gaining more seats at the table when policies and procedures that apply to people with disabilities are being changed.

I would like to tell you a little about myself. I have worked in the field of empowering people with disabilities for the past 30+ years.

My experiences include working with people with all types of disabilities by providing assistance, advising people on their rights, and helping to educate people who provide services to people with disabilities. I have worked for the California State Department of Developmental Services for 17 years as the Coordinator of Consumer Services. I provide a voice to the Director, and the Department, on issues and problems that people with disabilities may be facing in California and help to come up with solutions.

I also assist with the coordination of the Department's Consumer Advisory Committee (CAC) in their work on self-advocacy projects. I also participate on consumer-driven projects across the state. I am married and I have a beautiful 14-year-old daughter. I enjoy going to the movies and traveling. I look forward to assisting in leading the SSAN for the next two years.

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My name is Rebecca Donabed. I represent SCDD Sequoia Regional Office in the Central Valley. I work at Resources for Independence Central Valley (RICV) as a Community Organizer. I have been part of SSAN since 2012/2013 and am excited to take on the role of Secretary. I am active in my local community and are a part of several different committees including:

- Tulare County Voting Accessibility Advisory Committee (VAAC) as the Chair,
- Fresno County Voting Accessibility Advisory Committee (VAAC),
- Tulare County Social Service Transportation Advisory Committee (SSTAC) as the Vice Chair,
- Citizen Advisory Committee, SSAN Employment Workgroup-Chair,
- SCDD Employment Disability Expert Advisory Panel (DEAP),
- SCDD Regional Advisory Committee (RAC).

From 2016-2018 I was Secretary of SSAN and now I'm Secretary again. I was also on the State Council on Developmental Disability (SCDD) from 2012-2017.

Being on SSAN, to me, means that I can get better involved in my advocacy work on the state level and bring it back to my community.



Disability Voices United: Emerging Leaders Program

By Kecia Weller, UCLA TARJAN Center UCEDD SSAN Representative

What is the Emerging Leaders Program?

The Emerging Leaders Program is a five-part training program offered by Disability Voices United (DVU) that gives self-advocates with disabilities and family-advocates the skills needed to take leadership positions in their communities and state and to advocate for systemic change.

I attended the Emerging Leaders Program in 2022 and wanted to share my thoughts on the program. I feel that the Emerging Leaders Program is very similar to the Partners In Policymaking Leadership Program.

Here's some information on what you could learn through the Emerging Leaders Program:

Trainings include sessions on:

- Using your story to advocate for systemic change
- Telling your story using an “elevator speech” to get your message across in 60 seconds or less
- Learning about history of disability and how it impacts California legislation
 - I actually enjoyed the refresher session on disability history
- How disability leaders in California and the United States use social media for advocacy
 - You are encouraged to do homework on this topic and learn on your own
- How to advocate for better equity, outcomes, and self-determination
- Understanding the role of serving on a board or committee in the disability community
 - You are encouraged to attend your local regional center board and learn what it takes to be an effective board member.
- Ways to build a network with others in your community or state
- Identify two advocacy activities that you want to accomplish to make systematic changes in California and beyond

I really had a great time in the second cohort of Disability Voices United's Emerging Leaders Program. I learned quite a bit about how to utilize social media platforms to communicate with my elected officials. I recommend the Emerging Leaders Program to everyone because it's an excellent resource to learn leadership skills in a very supportive environment.



Everyone should **BE PREPARED** in case of an **EMERGENCY!**



By Robert Balderama, North Valley Hills SSAN Regional Representative

It is important for everyone to be prepared in an emergency. As I researched people with disabilities preparing for emergencies- I thought about earthquakes, floods, fires etc. It is important to know what to do and be prepared in each type of emergency. There are many resources out there to help people be prepared- check them out!

Take the example of earthquakes. How do you get prepared for earthquakes? It starts with practice; for instance, some people know to stand in a doorway and plant their feet wide and firmly and hold on as tight as you can on the frame. And or get under the nearest table on your knees or sit and bend your head if you can and brace yourself keeping your hands and feet under the table and your head down mouth closed so the debris won't get into your mouth.

So now, let's take me for instance. I'm in a wheelchair and I'm not sure what to do in case of an earthquake. As I searched for any information on what to do when an earthquake hits when you're in a wheelchair.

- First thing to do is, try your best to be calm so you can think clearly. I know that's easier said than done but try your best.
- Get in a clear space and or against a wall and lock your wheelchair and if you have anything to cover your head with, a book, laptop, picture frame, anything to protect your head from getting hurt.
- When you don't feel any more movement, check your surroundings to see if it's safe and clear to move about.

It is up to you to **BE READY** for any emergency! Get started **NOW!**

Resources to check out to be prepared for any type of emergency:

[Red Cross Resource: How to Prepare for Emergencies](#)

[California Office of Emergency Services](#)

You can also reach out to your SCDD Regional Offices for info and training in your region and your regional center- each regional center has an Emergency Coordinator that can give helpful information.



Water Safety

By Wesley Witherspoon, USC Children’s Hospital UCEDD SSAN Representative

Water Safety is important. Many people with disabilities drown in the water. Here are some tips to be safe around the water.

1. If you can’t swim, do not get into the water.
2. Stay far away from the water, waves can occur quickly.
3. If you are a swimmer, make sure that there is a lifeguard to help you if decide to swim.
4. If you are an experienced swimmer only swim where the water is not too deep.
5. Wear a life vest if you decide to swim.
6. When you are done swimming, make sure that you stay away from the water.
7. Do not dive, unless you are experienced diver and have a lifeguard nearby.
8. Even if you are at a beach, do not even try to put your feet in the water, waves can occur fast.
9. Listen to weather warning and pay attention to the surf and waves if you go to the beach.
10. Make sure there is someone else around, if you go near the water.
11. Do not go out to the water at night.
12. If you go on a boat or ship, make sure you know the safety tips to be safe.
13. Do not play around if you go in the water.
14. Wear Scuba gear if you decide to swim and dive.
15. If you have accessibility needs, make sure that the water source is accessible.

As it gets warmer, use these tips when you might swim.

SSAN Members

- Nathaniel Florez – North Coast
- Charles Nutt – North State
- Lisa Cooley – Sacramento
- Ellen Sweigert – North Bay
- Regina Woodliff – Bay Area
- Robert Balderama – North Valley Hills
- David Forderer – Central Coast
- Rebecca Donabed – Sequoia
- Julie Gaona – Los Angeles
- Sean Sullivan – Orange County
- Eric Aguilar – San Bernardino
- Paul Mansell – San Diego Imperial
- Desiree Boykin – ARCA
- Goldie House – CFILC
- Nicole Patterson – DDS
- Scott Barron – DRC
- Robert Levy – UC Davis Mind Institute
- Kecia Weller – UCLA Tarjan Center
- Wesley Witherspoon – SCDD and USC Children’s Hospital
- Maria Marquez – SCDD



Organization Spotlight: Hand in Hand

By Lisa Cooley, Sacramento SSAN Regional Representative



HAND IN HAND THE DOMESTIC EMPLOYERS NETWORK

Hand in Hand is an organization that is dedicated to improving the quality of life for domestic workers (housekeepers, nannies, house cleaners and attendants and home health care aides). The organization also advocates on behalf of domestic employees and people who have various disabilities. Hand in hand is currently working on increasing wages for IHSS workers to 20 dollars per hour in California. Russell Rawlings is the education organizer for Hand in Hand. As the education organizer he educates members of the organization and the community about the issues that affect domestic workers and IHSS recipients. One of the biggest advocacy activities that Hand in Hand will be involved in is bringing together local disability advocates to help increase wages for attendants. They also advocate for improving the health and safety of domestic workers. I got involved because I was invited to a meeting and learned about what they do and how to get involved and become a member. The organization has dues that are 36 dollars a year or 3 dollars a month if someone has a low income. The dues are used to help support the mission of the organization.

I am becoming a member of the organization to increase my advocacy in a new direction that is cross-disability advocacy.

SSAN Mission Statement

The Statewide Self-Advocacy Network (SSAN) promotes leadership and builds bridges that strengthen advocacy among disability communities by focusing on policy change.

[SSAN's past Newsletters, Annual Reports, and Meeting info](#), can be found at www.scdd.ca.gov under the "Self-Advocacy" tab

Let us know if you want to see anything specific in future newsletters!

How do you contact the SSAN Newsletter Editor Robert Levy? Leave a message for him by contacting the SCDD Self-Advocacy Coordinator **Riana Hardin at (916) 263-8196**

Check out the [SCDD YouTube Page](#) for stories from self-advocates, past meetings, and more!

Self-Advocacy through Self-Employment

By Paul Mansell, San Diego Regional SSAN Representative



In September I retired from San Diego Regional Center (SDRC) and in October, I started a 9-week class to become a certified Independent Facilitator for the Self-Determination Program of the Regional Centers. The course was expensive, more than I could afford, but I received a scholarship to attend it. My SDP covered the costs of what the scholarship didn't. Through the class, I learned that the field consists mainly of individual providers, so while taking the course and being busy with coursework, I set up my business, which became a full-time job.

I named my company—PFM Solutions, got my logo, business license, office supplies, business cards, business email address paulmansell@pfmsolutions.co and website <https://pfmsolutions.co/>, doing the website myself. I opened business checking and savings accounts and got a business credit card. I purchased office supplies and subscribed to many web-based online services. I developed a host of computer skills and knowledge.

I was so proud when I got my course completion certificate and hung it on the wall. All this took a considerable amount of time, effort, and finances. I opened for business on January 1, 2023, to receive clients and submitted paperwork to become a vendor of SDRC.

My business motto is “Move from the unknown to your North Star.” My mission statement is to empower participants and their families to grow and lead happy, successful, and purposeful lives to their full potential with appropriate support in the community of their choice. My vision is to see clients live happy and satisfying lives thanks partly to their self-determination plans. My Self-Determination Plan covers much of my operating expenses. I want to serve clients throughout California and receive an income that will let ends meet. Since I will help clients statewide, I will conduct my business virtually over Zoom.

I am a one-person show running my business. This means I am the administrator, administrative assistant, IT & PR Department, and bookkeeper, besides being an IF. Accordingly, I must learn many software programs and online services, budget my time well, and be organized. Most importantly, I must remember my people skills. This is all very challenging but exciting at the same time. Watching videos on YouTube helps. I will be harnessing my full potential for the first time.

I am eager to have my first client. To fill the time, I am designing and developing my database. It will help me stay organized once I have clients on-board.

The 411 on Voice Options

By **Rebecca Donabed**, Sequoia Regional SSAN Representative



In July 2022, through DOR and Resource for Independence Central Valley (RICV) I got into the Voice Option program. The [Voice Option Program](#) provides a talking app to help people with disabilities who can't speak very well or at all. Voice Option has 6 applications: GoTalk NOW Plus, LAMP Words for Life, Predictable, Proloquo2Go, Proloquo4Text and TouchChat HD with WordPower. Applicants get a loaner iPad for 1 month to see if they really like it and what app works best for them. Then they give the loaner iPad back and receive a new iPad with their chosen app already downloaded to it.

I chose Proloquo2Go. This has been a total game changer for me. I mainly use it for work when I need to give a presentation and when I need to talk on the phone. I can better organize my thoughts on my iPad and then press 'speak' and it says what I wrote, and I also have it on my iPhone. I also found out that I can talk to Amazon's "Alexa" with it. I had something like this when I was in elementary school, but when I went to middle school, it never went along with me. I have always wanted to find something similar to that 'talker' but didn't know how to go about it; and now I have it.



Emergency Preparedness Tips

By Eric Aguilar, San Bernardino SSAN Regional Representative

Disasters are classified into natural disasters, man-made disasters, and hybrid disasters.

Disasters can strike quickly and without warning. They can force you to evacuate your neighborhood, school or workplace or confine you wherever you are. A Disaster supply kit is a collection of items that may be needed during or after an emergency or disaster. Sometimes called a 72-hour kit, survival kit, emergency preparedness kit, or bug-out kit, these kits can be important to the safety of you and your household. As you put your kits together, remember to consider these factors:

- What container(s) to use – Some may require a large plastic tub, but a couple of backpacks may do as well.
- Where to store your kit – Make sure it will be accessible when you need it.
- How will you maintain your kit? – Check it regularly and have a plan to replace expired or out-of-date items.
- Consider other types of kits you may need – One big kit at home is a great start but consider keeping a kit in other places you may be when an emergency occurs such as at work, in your car, or on vacation.

In addition to having your basic survival supplies, an emergency kit should have items to meet your individual needs in various emergencies. Consider the items you use every day and which ones you may need to add to your kit.

Tips for Medications

- Talk to your doctor or pharmacist about how you can create an emergency supply of medicines.
- Keep a list of your prescription medicines. Include information about your diagnosis, dosage, frequency, medical supply needs and allergies.
- Store extra nonprescription drugs, like pain and fever relievers, antihistamines, and antidiarrheal medicines.
- Have a cooler and chemical ice packs available to chill medicines that need to be refrigerated.

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Disability Related Items to Pack

- Extra hearing-aid batteries
- Pen and paper (in case you have to communicate with someone who does not know sign language)
- Extra battery or charger for power wheelchairs
- Manual wheelchair
- Assistive technology items like iPads and communication cards
- Medical/disability history
- Battery operated lantern to enable communication by sign language or lip reading, especially when the electricity is out and it's dark.
- Consider keeping a patch kit or can of sealant for flat tires and/or extra inner tube if the wheelchair or scooter is not puncture proof.
- Other mobility devices like canes and walkers

General Items to Pack

- Radio (consider one)
- Flashlight/battery operated lantern
- Chargers
- Electronics like iPads and laptops
- Pen and paper
- Noise canceling headphones
- Snacks (non-perishable)
- First aid kit
- Clean clothes
- Important documents
- Hygiene items
- Extra money (cash)
- Pillow and blanket

Communicate with neighbors who can assist you if you need to evacuate the building and keep a list of names and numbers of family and friends to communicate with. You should also consider signing up for local and statewide alerts. Stay tuned for more info on emergency preparedness in future editions of this newsletter!

Member Bio: Goldie House CFILC SSAN Rep

By Goldie House, CFILC SSAN Representative



Hi, my name is Talmadge House, but everyone calls me Goldie. I am excited to be representing CFILC on SSAN and wanted to tell you a little about myself.

I have a history in Advocacy. Before I was hired to work for CFILC, I worked with an Independent Living Center for 5+years and have more than 20 years combined advocacy a self-advocacy experience. I have been a member of CFILC's (DOnetwork) Disability Organizing Network since about 2018.

I am the Statewide Community Organizer for CFILC. In my role, I assist and support the 28 Independent Living Centers (ILCs) that are part of the IL Network, participate in statewide disability and/or intersectional coalitions (like SSAN), develop community organizing campaigns that promote systems change, and organize regional and statewide community events.

I consider CFILC "ILC-Mothership" for statewide advocates & organizers. I look forward to supporting changes in our communities, focusing on empowering our choices & options for continued Independence.

My Moto is to (ACCEPT/ADAPT/ADJUST) = main keys to our survival. My approach to advocacy is each 1 teach 1. Someday soon we all may reach One...

I am currently a member of an In-Home Supportive Services (IHSS) Advisory Committee since February 2018.

The DOnetwork wants to collaborate with Statewide Self-Advocacy Network (SSAN), in continuing to increase knowledge and visibility about Independent Living, resulting in positive changes in communities, assuring options and choices throughout California for our I/DD Individuals.

The Disability Organizing network is a collaborating team of Advocates and Organizers throughout California's 28 Independent Living Centers (ILCs) whose priorities include ensuring equity and inclusion. The is done by connecting our impacted communities with legislative voting information, communication skills, and community organizing strategies to advance our I/DD & Independent Living Movement.



DDS' CAC is RECRUITING!

The Department of Developmental Services (DDS) Consumer Advisory Committee (CAC) provides advice to DDS on policies, programs, legislation, and regulations that affect the lives of Californians with intellectual and developmental disabilities.

About the CAC:

- ☀ Fifteen (15) self-advocate members from all over California
- ☀ Meets at least four (4) times a year in Sacramento, or online with Zoom
- ☀ Members share information with their local self-advocacy organizations
- ☀ Brings input from those groups back to the CAC
- ☀ Transportation, hotel, meal, and facilitator costs (if needed) will be paid by DDS

If you would like to apply to be a CAC member, here is what you need to do:

- * Check the link below to see if we are recruiting from your regional center.
- * You must have an intellectual or developmental disability and receive regional center services to apply.
- * You must be a member of a local self-advocacy group or other organization that serves or empowers people with developmental disabilities.
- * You **MUST** be nominated for membership by your local self-advocacy group or developmental disability organization.

Please note: Regional Center employees are not eligible for CAC membership.



Interested advocates should fill out the online [DDS Consumer Advisory Committee Application](#) and submit it with their nomination letter.



Good News Corner

Here are some examples of websites that you can find uplifting news:

- [The Good News Network: California](#) for up-to-date information about interesting positive things that are happening
- [Positive News](#) is a site that you can check out to see what is happening around the world that is positive
- [Good Good Good](#) shares really good news, not just feel-good news
- [Happy News](#) celebrates all that is good in the world
- [Optimist Daily](#) is a site that shares solutions and good news from around the world

Disability-Related Reads and Podcasts

Here are a few Self-Advocacy and Disability-related publications that SSAN members are reading:



[Disability Scoop](#) is an online resource with disability-related news



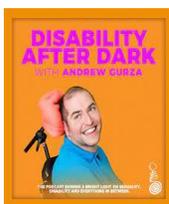
[Social Security Administration Blog](#) has SSI information



[World Institute on Disability News](#) has updates on what is happening around the world



[RespectAbility News](#) has updates on national efforts to engage people with disabilities in the political process





Kudos Corner



By Nicole Patterson, California Department of Developmental Services
SSAN Representative

Robert Balderama takes his job representing the North Valley Hills Regional Office and Self Advocacy Council 6 on the SSAN to heart. He has been an advocate and a fighter for the underdog, for not only people with disabilities but for other civil rights movements throughout his career as an activist for at least 50+ years.

Robert believes that everyone deserves to be treated equally in every way. He is the kind of SSAN member that always treats everyone the same by showing respect and kindness. He has a passion for the youth and understand how important it is to give them a voice. He has been committed to the vision of the SSAN since the beginning. Roberts sits on Valley Mountain Regional Center Board and several different SSAN workgroups and is always willing to offer his time and wisdom to help move the work forward. Robert, the SSAN would not be the same without you. Kudos to you!!

Mark your calendars!

Event: 2023 Statewide Self-Advocacy Conference

Date: May 12-13, 2023

Location: In-Person at the Wyndham Hotel in Sacramento, CA (formerly the Crown Plaza

Conference Theme: Leaping Forward

Visit <http://supportedlife.org/> to learn more!



Learn About SSAN Member Organizations

- [Association of Regional Center Agencies](#)
- [California Foundation for Independent Living Centers](#)
- [Department of Developmental Services](#)
- [Disability Rights California](#)
- [University of California, Davis MIND Institute](#)
- [University of California, Los Angeles, Tarjan Center](#)
- [University of Southern California, Children's Hospital](#)

Self-Determination Update

Self-Determination is LIVE in California. Check out the [DDS Self-Determination Newsletter](#) for the latest on California's Self-Determination Program. Talk to your service coordinator to learn more.



Tips for Staying Positive in Trying Times

There is so much happening in our communities right now and at times it can feel over whelming. Here are some tips for keeping calm that we want to share with you:

- Remember your ABC's: Always Be Caring
- Listen to music: your favorite artist, or type of music
- Have a dance party and move around
- Try boxing or Thai Chi
- Talk to a friend or family member
- Mentor another advocate
- Write about how you are feeling or thinking
- Read and learn something new
- Go for a walk or jog outside: fresh air is good for you
- Check out a coffee/tea shop and people watch
- Volunteer for an issue that you care about
- Share your story/experiences with others
- Get plenty of rest to feel energized for the next day
- Try to eat healthy
- Practice Yoga/stretching or mindful meditation
- Know that you are not alone
- Stay involved in your community by joining a board

Community Resources

[SARTAC Zoom Meetings](#)

[ARCA Regional Center COVID-19 Resources](#)

[DRC's Build Back Better Resources](#)

[SSA Ticket to Work Tips to Open Your ABLÉ Account](#)

[Office of Self-Determination Ombudsperson](#)

[US Dept Of Education Office of Civil Rights Digital Access Series](#)

[How to Talk about Disability Sensitivity](#)

SAVE THE DATES

Disability Rights California



[Events and Trainings](#)

CalABLE



[News and Trainings](#)



[DO Network Training Library](#)

Plain Language COVID-19 Resources Available on: [SCDD Website](#)

Register for the Monthly California Statewide Self-Advocacy Chats on Zoom



[Current Issues and Resources](#)

[Voting Resources](#)

**DRC Voting Hotline:
888-569-7955**

[Disability Vote California](#)

Have questions about the Self-Determination Program? [The Self-Determination Advocates Leadership Group](#) meets monthly on Zoom

Help Save A Life!

Join Project Self-Advocates for Emergency Education (SAFEE) a FREE Hands-Only CPR Training

The 2nd Friday of every month
Starting in January of 2023 Register
for **one** class only
(Non-certified training)
Limited to (30) people

Date	Time
April 14 th	9:00 am – 10:30 am
May 12 th	9:00 am – 10:30 am
June 9 th	9:00 am – 10:30 am

2 STEPS TO SAVE A LIFE



Participants will learn:

- ❖ How to do hands-only CPR
- ❖ When to call 9-1-1

To get ready for Practicing Hands-Only CPR:

Find one of the following in your home



Empty disposable water bottle with cap



Rolled up yoga mat



Toilet paper roll!



Foam stress toy

Or... something that you can compress about 2" and it pushes back!

Registration Zoom Link:

https://bit.ly/ARCProjectSAFEE_CPRTraining

Habr  interpretaci n en Espa ol disponible

For more information, or if you need an accommodation to participate in these

trainings, please contact in advanced:

Debbie Marshall: debbie.marshall@scdd.ca.gov

Jennifer Lucas: jennifer.lucas@scdd.ca.gov

with your request at least **5** days prior to the training date.

In collaboration with:

